

Effect of Structured Parental Education on Parental Support and Quality of Life of Children with Thalassemia in Indonesia: A Quasi-Experimental Study

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ABSTRACT

Introduction: Thalassemia is a lifelong hereditary blood disorder that requires continuous treatment and family involvement. Parents play an important role in supporting medical adherence and emotional stability in affected children. However, limited knowledge and coping difficulties may reduce the consistency and quality of parental support. This study explored whether a structured parental education program based on the Health Belief Model could improve parental support and children's quality of life.

Methods: A quasi-experimental pretest–posttest control group design was used. Fifty-six parents of children with thalassemia were included and divided into an intervention group (n = 28) and a control group (n = 28). Participants were recruited through random sampling at a regional referral hospital between June and December 2023. The intervention involved structured face-to-face education sessions addressing disease information, emotional support strategies, communication skills, and home care practices. Parental support was measured using a validated multidimensional questionnaire, and children's quality of life was assessed with a standardized instrument. Data were analyzed using Wilcoxon Signed-Rank and Mann–Whitney tests with a significance level of $p < 0.05$.

Results: After six weeks, parental support scores increased in the intervention group from a median of 31.50 to 37.00 ($p < 0.001$), while the control group showed no significant change ($p = 0.069$). Children's quality of life scores also improved significantly in the intervention group compared with the control group ($p < 0.001$). The magnitude of improvement was greater among parents who received the educational program.

Conclusion: Structured parental education was associated with improved parental support and better quality of life in children with thalassemia. Integrating parent-focused education into routine care may strengthen family involvement and support more holistic management of chronic conditions.

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INTRODUCTION

Thalassemia is a hereditary blood disorder caused by impaired hemoglobin production, resulting in chronic anemia that requires continuous medical care throughout life (1,2). Children diagnosed with thalassemia major commonly undergo regular blood transfusions combined with iron chelation therapy to prevent serious complications such as heart failure, endocrine disturbances, growth impairment, and decreased physical functioning (3,4).

However, the impact of thalassemia extends beyond physical symptoms. Many affected children experience emotional distress, social challenges, treatment fatigue, and lowered self-confidence. These psychosocial burdens can substantially influence their overall quality of life (5,6). Living with a chronic condition from an early age often requires long-term adjustment, both for the child and for the family.

Within this context, parents hold a pivotal role. Their involvement influences treatment adherence, emotional stability, and the child's ability to cope with ongoing health demands (7). Parental support is not limited to practical caregiving tasks. It also includes emotional reassurance, clear communication, guidance, and encouragement that shape a child's psychological well-being (8–10). Despite this central role, many parents of children with thalassemia report feeling uncertain, overwhelmed, or insufficiently informed. Limited knowledge about the disease, anxiety related to complications, and emotional exhaustion may reduce their confidence in providing consistent and effective support. When these challenges persist, the child's adaptation and quality of life may be affected.

Educational interventions for parents have been explored in various chronic pediatric conditions. Evidence suggests that structured education can improve disease understanding and strengthen caregiving confidence (11–15). Yet, many existing programs focus primarily on delivering medical information or improving treatment compliance. Fewer interventions explicitly address multidimensional parental support or evaluate its direct impact on children's quality of life—particularly in thalassemia populations within low- and middle-income settings. Furthermore, research examining theory-based educational programs that simultaneously target parental behavior and child outcomes remains limited and methodologically varied.

To address this gap, the present study implemented a structured parental education program grounded in the Health Belief Model. The program integrates disease-related knowledge with emotional coping strategies and practical caregiving skills. Rather than concentrating solely on knowledge acquisition, the intervention was designed to strengthen supportive behaviors that may directly influence children's well-being.

This study examines whether such an approach can meaningfully improve parental support and enhance the quality of life of children living with thalassemia. By focusing on family-centered empowerment, the findings are expected to contribute to the development of more holistic nursing interventions and support the integration of structured parent education into routine thalassemia care.

METHOD

This research used a quasi-experimental design with a pretest–posttest control group approach. The design was selected to evaluate changes in parental support and children's quality of life before and after the implementation of a structured parental education program. Two groups were observed: an intervention group that received the educational program and a control group that continued to receive standard care.

Participants and Sampling

Participants were parents or primary caregivers of children diagnosed with thalassemia who were receiving routine treatment at a regional referral hospital. A total of 56 respondents were included in the study. They were recruited from the eligible population using random sampling procedures. Assignment into intervention and control groups followed a quasi-experimental framework rather than full randomization. Group placement was determined based on clinical scheduling and logistical considerations to ensure feasibility without disrupting routine services. Eligibility criteria included biological parents or primary caregivers of children aged 6–18 years with a confirmed diagnosis of severe thalassemia and a history of regular blood transfusions within the previous six months. Caregivers of children who had additional chronic illnesses or psychiatric conditions were excluded in order to minimize potential confounding influences on psychosocial outcomes.

Study Setting

The study was conducted at a regional referral hospital in Indonesia that provides specialized pediatric hematology services. The hospital serves as a primary center for blood transfusion therapy and long-term thalassemia management.

Instruments

Parental support was assessed using a validated multidimensional questionnaire adapted from the Multidimensional Scale of Perceived Social Support. The instrument captures four domains: emotional support, informational support, instrumental assistance, and appraisal support. Responses are recorded on a four-point Likert scale ranging from 1 (never) to 4 (always). Children's quality of life was measured using the Pediatric Quality of Life Inventory (PedsQL™ 4.0 Generic Core Scales). This instrument is commonly used to assess health-related quality of life in pediatric populations with chronic health conditions. Previous studies have reported satisfactory validity and reliability of the PedsQL across diverse clinical groups, including children with hematological disorders. In the present study, the instrument demonstrated high internal consistency, with a Cronbach's alpha above 0.90.

Intervention and Data Collection

Data collection was carried out in two phases. Baseline measurements were obtained during routine clinical visits before the intervention was delivered. After completing the pretest assessment, parents in the intervention group participated in structured face-to-face education sessions facilitated by trained personnel. The educational content covered basic disease information, transfusion management, emotional support strategies, communication techniques, and home-based care practices. Supporting printed materials were provided to reinforce key points discussed during the sessions. Follow-up assessments were conducted six weeks after the intervention. During this period, the control group continued receiving standard clinical care without additional structured education. Posttest measurements were then collected to evaluate changes in parental support and children's quality of life.

Data Analysis

Data analysis involved both descriptive and inferential procedures. Participant characteristics and baseline variables were summarized using descriptive statistics. Tests of normality were conducted prior to selecting inferential analyses. For variables that did not meet normality assumptions, non-parametric tests were applied. Changes within groups were examined using the Wilcoxon Signed-Rank test. Differences between intervention and control groups were analyzed using the Mann–Whitney test. For normally distributed variables, parametric tests were used accordingly. Statistical significance was determined using a p-value threshold of less than 0.05. Continuous data were presented as means with standard deviations when normally distributed and as medians when distributions were skewed. This approach was adopted to ensure that statistical interpretation remained appropriate and transparent.

Ethical Approval

Ethical approval was granted by the Research Ethics Committee under approval number 104.6/II.3.AU/F/KEPK/V/2023, issued on May 8, 2023. Prior to participation, all respondents received detailed explanations regarding the study objectives, procedures, confidentiality measures, and their rights as participants. Written informed consent was obtained from each participant. They were informed that participation was voluntary and that withdrawal at any time would not affect their access to medical care.

RESULTS

Analysis of the baseline demographic variables showed that the intervention and control groups were similar at the start of the study. No significant differences were found in parental age, gender, education level, occupation, length of caregiving, or in the child's age and gender ($p > 0.05$), as summarized in Table 1. This suggests that both groups began the study under comparable conditions, making it less likely that demographic factors influenced the outcomes.

Over the six-week observation period, the control group did not show meaningful changes. Parental support scores remained at a median of 32.00 before and after the study ($p = 0.069$). Children's quality of life scores changed

only slightly, from 64.47 to 65.00, and this difference was not statistically significant ($p = 0.577$), as presented in Table 2. In practical terms, routine care alone did not appear to alter parental support patterns or improve children’s well-being during the study period.

Table 1. Respondents’ Characteristics by Study Group (n = 56)

Variable	Category	Control (n=28)	Intervention (n=28)	Total (n=56)	p-value
Parent age (years)	Mean ± SD	36.8 ± 7.2	37.4 ± 6.9	37.1 ± 7.0	0.742
Parent gender	Male, n (%)	6 (21.4)	7 (25.0)	13 (23.2)	0.752
	Female, n (%)	22 (78.6)	21 (75.0)	43 (76.8)	
Education level	Primary	8 (28.6)	7 (25.0)	15 (26.8)	0.834
	Secondary	14 (50.0)	15 (53.6)	29 (51.8)	
	Higher education	6 (21.4)	6 (21.4)	12 (21.4)	
Occupation	Employed	17 (60.7)	18 (64.3)	35 (62.5)	0.794
	Unemployed	11 (39.3)	10 (35.7)	21 (37.5)	
Duration of caregiving (years)	Mean ± SD	5.8 ± 2.6	6.1 ± 2.4	6.0 ± 2.5	0.658
Child age (years)	Mean ± SD	10.7 ± 3.1	11.0 ± 3.0	10.9 ± 3.0	0.721
Child gender	Male, n (%)	15 (53.6)	14 (50.0)	29 (51.8)	0.785
	Female, n (%)	13 (46.4)	14 (50.0)	27 (48.2)	

Table 2. Changes in Parental Support and Children’s Quality of Life in Control Group (n=28)

Variable	Before (Median)	After (Median)	p-value	Test
Parental support	32.00	32.00	0.069	Wilcoxon Signed-Rank
Children’s quality of life	64.47	65.00	0.577	Wilcoxon Signed-Rank

Table 3. Changes in Parental Support and Children’s Quality of Life in the Intervention Group (n = 28)

Variable	Before	After	p-value	Test
Parental support	31.50 (Median)	37.00 (Median)	<0.001	Wilcoxon Signed-Rank
Children’s quality of life	65.51 ± 1.47	70.36 ± 1.75	<0.001	Paired t-test

Table 4. Comparison of Changes Between Control and Intervention Groups (n = 56)

Variable	Group	Mean Rank / Δ Score	p-value	Test
Parental support	Control	0.93 ± 2.34	<0.001	Mann–Whitney
	Intervention	4.57 ± 3.05		
Children’s quality of life	Control	0.35	<0.001	Mann–Whitney
	Intervention	4.98		

A different pattern emerged in the intervention group. After participating in the structured parental education sessions, parental support scores increased from a median of 31.50 to 37.00 ($p < 0.001$). This shift reflects a noticeable improvement in caregiving involvement and supportive behaviors. Children’s quality of life also improved during the same period. The mean score rose from 65.51 ± 1.47 to 70.36 ± 1.75 ($p < 0.001$), as shown in Table 3.

When comparing both groups directly, the differences became clearer. The average increase in parental support was 4.57 ± 3.05 in the intervention group, compared with 0.93 ± 2.34 in the control group ($p < 0.001$). A similar trend was observed for children’s quality of life. The intervention group improved by 4.98 points, while the control group showed only a 0.35-point increase ($p < 0.001$). These results point to a meaningful contribution of the educational program to the observed improvements.

DISCUSSION

The results of this study show that structured parental education was associated with meaningful improvements in both parental support and children’s quality of life. Parents who participated in the intervention displayed stronger supportive behaviors after six weeks, while those in the control group showed little change. A similar pattern was seen in children’s quality of life scores. These parallel improvements suggest that strengthening parental involvement may play an important role in shaping children’s well-being in the context of chronic illness. Caring for a child with thalassemia involves more than managing transfusion schedules and medical appointments.

It also requires emotional resilience, consistent encouragement, and clear communication within the family. When parents feel better informed and more confident in their caregiving role, their interactions with their children may become more supportive and structured. Over time, this can influence how children perceive their condition and adapt to ongoing treatment demands.

Previous research has reported that educational programs for parents can improve coping strategies and reduce caregiver burden in families affected by thalassemia (16–19). Many of these studies, however, have focused primarily on parental stress or knowledge levels. The present study expands that perspective by examining both parental support behaviors and children's quality of life within the same framework. By doing so, it highlights the interconnected nature of caregiver behavior and child outcomes.

Many earlier investigations relied on descriptive or cross-sectional designs. While those approaches are valuable for identifying associations, they offer limited insight into causal relationships or intervention effects. In the present study, a quasi-experimental pretest–posttest control group design was applied within the framework of the Health Belief Model. This approach allowed clearer observation of change over time and provided stronger support for the relationship between structured parental education and improvements in caregiving behaviors as well as psychosocial outcomes among children with thalassemia. Previous research has often concentrated on parental knowledge or levels of stress. In contrast, this study examined changes in multidimensional parental support together with children's quality of life (20,21). Assessing both dimensions simultaneously offers a broader understanding of how parental engagement may influence child well-being. Evidence on theory-informed, family-centered educational programs in thalassemia care remains relatively limited, particularly in low- and middle-income settings. By combining disease education with emotional support strategies and practical caregiving skills, the present intervention demonstrated measurable benefits beyond routine clinical care.

The choice of a quasi-experimental design also strengthens the interpretation of these findings compared with purely observational studies. Although it does not eliminate all potential sources of bias, it enables a more structured evaluation of intervention effects over time. In this sense, the study adds to the growing literature supporting family-centered strategies in the management of chronic pediatric conditions (22–24). The findings also have practical implications for nursing care. Nurses are often the professionals who maintain continuous contact with families managing long-term illnesses. Through structured education sessions, they can guide parents not only in understanding the disease but also in developing coping strategies and communication skills that support effective caregiving (25–27).

Embedding parent-focused educational components into routine services—particularly in outpatient clinics and transfusion units—may help strengthen treatment adherence and family resilience. Positioning parents as active partners in care, rather than passive recipients of information, aligns with the principles of family-centered practice and may contribute to more sustainable improvements in child well-being (28,29).

One aspect that distinguishes this study is the way it combines theoretical grounding with the assessment of two related outcomes. Many earlier interventions have concentrated either on caregiver-related variables or on child outcomes separately. In this research, parental support and children's quality of life were examined together. Looking at both dimensions within the same framework allows a clearer view of how changes in parental behavior may be reflected in children's daily functioning and well-being. The intervention was designed within the Health Belief Model, linking parents' perceptions and beliefs with practical caregiving actions (30,31). Rather than treating theory as a conceptual backdrop only, it was used to structure the educational sessions and guide behavioral reinforcement. This connection between belief, action, and outcome helps explain why improvements were observed not only in parental support but also in children's quality of life.

It should also be recognized that parental education programs do not always produce consistent results. Some studies have reported limited or mixed effects, particularly when interventions focused mainly on information transfer without addressing emotional or behavioral components of caregiving (32–34). Differences in program intensity, duration, cultural context, and research design may contribute to these variations.

In the present study, the intervention combined disease-related education with emotional support techniques and communication guidance. Addressing these elements together may have strengthened its overall impact (35). Considering both parent and child outcomes provides a more balanced perspective and situates the findings within the broader discussion on family-centered care in chronic pediatric conditions.

Despite the encouraging results, several limitations must be considered. The sample size was modest and participants were drawn from a single hospital, which may limit the general applicability of the findings. The six-week follow-up period was relatively short, making it difficult to determine whether the observed improvements would remain stable over time. In addition, reliance on self-reported measures introduces the possibility of response bias, including socially desirable reporting. Future research involving multiple institutions, larger samples, and longer follow-up intervals would help clarify the durability of the intervention effects. Such studies could also explore how structured parental education influences longer-term clinical and psychosocial outcomes in children with thalassemia.

CONCLUSION

The findings of this study suggest that structured parental education can improve both parental support and the quality of life of children with thalassemia. Parents who attended the educational sessions appeared more confident in their caregiving role and showed greater emotional engagement compared to those who received routine care alone. This indicates that supportive behavior does not develop automatically; it benefits from clear guidance and structured learning opportunities. Incorporating parent-focused education into regular thalassemia services may therefore strengthen everyday caregiving practices. When parents better understand the condition and feel equipped with practical coping strategies, they are more prepared to respond to their child's needs. Over time, this may contribute to improved psychosocial well-being for children living with chronic health conditions.

AUTHOR CONTRIBUTION STATEMENT

Conceptualization, W.U., M.N. and K.M.; Methodology, W.U. and M.N.; Software, W.U.; Validation, W.U., M.N., and K.M.; Formal Analysis, W.U. and P.A.W.S.; Investigation, W.U., M.N. and K.M.; Resources, W.U. and P.A.W.S.; Data Curation, P.A.W.S.; Writing – Original Draft Preparation, W.U. and P.A.W.S.; Writing – Review & Editing, W.U. and P.A.W.S.; Visualization, P.A.W.S.; Supervision, W.U., M.N. and K.M.

CONFLICTS OF INTEREST

All authors declare to have no conflict of interest.

DECLARATION OF GENERATIVE AI AND AI-ASSISTED TECHNOLOGIES IN THE WRITING PROCESS

The author uses Grammarly to assist in language refinement during the manuscript preparation process.

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